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ABSTRACT

Two rural Ojibwe mothers whose young children received early childhood at-risk services were interviewed about their life circumstances and experiences with service delivery. Major interview themes that emerged included positive experiences and successes with early childhood special education services, and rural and cultural obstacles to the effectiveness of services. The non-Native early childhood professional who served the children of both women was viewed as genuine, knowledgeable, and capable of sharing her knowledge without pretense or criticism of the families. The mothers' high level of comfort with this professional, who frequently visited them in their homes and who advocated for them in interactions with bureaucrats and medical personnel, underscores the importance of a service provider's personal style to program success. Both children's conditions improved as a result of timely and consistent early intervention services. The mothers also experienced various obstacles to the effectiveness of services: distance to appropriate medical care; pessimistic attitudes and lack of active listening on the part of doctors and other medical personnel; and lack of trust by Native American families toward non-Native professionals due to disabled Native children being removed from their families in the past. Other interview themes included the positive contribution of Native traditional values to the children's outcomes, spiritual feelings, the difficult choice between the tribal school's cultural strengths and the local public school's extra services, and support received from the family's medicine man. (SV)

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1

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RURAL OJIBWE MOTHERS' EXPERIENCES WITH EARLY CHILDHOOD SPECIAL EDUCATION SERVICES

Working with young children on an Indian Reservation brought to my attention factors which interfered with service provision. Great effort was expended by students and staff traveling to and from the school each day. Winter weather frequently made travel arduous and sometimes impossible. It required several years of daily association to build rapport with mothers. My errors of cultural misunderstanding were met either with good humor or a resigned defensiveness. Problems with service delivery seemed to me twofold: First, reservation areas tended to be remote. Thus, problems associated with ruralness were present. Second, cultural clashes and misunderstandings frequently entered the picture.

While working in this environment, I became sensitive to the opinions of Ojibwayan people, though I also worried that seeking answers to my questions about needs and culture could be seen as intrusive, or paternalistic. Nonetheless, over four years, I developed rapport with families from several different Native American communities. Concerns and successes were shared with sincerity and growing trust.

In the spirit of learning through hearing, I sought to converse with Ojibwayan mothers of students receiving early childhood at-risk services. Bureaucratic requirements for such things as eligibility determination seemed a natural focus for cultural conflicts. In addition, most providers [in my locale] were European Americans. In short, I was interested in how a system such as early childhood special education interacted with the culture of reservation mothers, particularly given their importance as purveyors of traditional ways of life (Coggins, 1996). Coggins noted for example that traditional Ojibwayan maternal values correlated positively with offsprings' social and academic competence. For many American Indian groups, "Strong female leadership in both family and community has long been a part of the culture" (Coggins, 1996, p.14).

Economic disadvantage is endemic on reservations in the upper Midwest (Schneider, 1994). For example, estimates of unemployment rates (not even mentioning underemployment) on reservations in the United States range from 30 to 90%, with an average unemployment rate of approximately 45% nationwide (Levitan & Miller, 1993). Mythology of the larger culture often supposes that more resources are available to Native Americans than is the case:

Closely associated with the myth that Indian people get regular checks from the Federal government is the erroneous idea that Indian people get special assistance and programs that are not available to non-Indians (Schneider, 1994, p. 185).

It is probable that disadvantaged economic circumstances may also affect mothers' interactions with early childhood services. For example, economics may make it difficult to access center-based programs at a distance from the home. Some families, in my experience, have no telephones.

Based on the 1990 census, American Indians experience disability at one-and-a-half times the rate of the general population. Nearly 17% of the enrollment of Bureau of Indian Affairs schools require special education services (Morgan & O'Connell, 1986). The number of Native American children with disabilities served by Indian Headstart programs increased from 8.7% in 1979-80 to 11.52% in 1984-85. Of the 8,500 to 12,800 preschool children ages 3 and 4 with disabilities, 3000 were on 63 reservations served by Bureau of Indian Affairs (BIA) schools. Of those three thousand, 838 were receiving special education services in 1988-89. It was estimated that between 2,110 and 2,948 children on reservations served by BIA schools might need, but were not receiving, special education services. Nearly one fourth of 791 children with Individual Education Plans (IEPs) were not receiving all services prescribed in their IEPs. Those receiving inadequate services were likely underestimated since IEPs often specify available services rather than those a child actually needs (Johnson, 1991).

Some categories, such as mental retardation and hearing impairment, were reported to be lower than the national rate within the BIA. However, as the percentage of Native American students increased by 8%, special education enrollment increased 41.8%. Over the same period, 80% of American Indian children in special education were in learning disability or speech impaired categories (Johnson, 1991).

Because of the above factors, I interviewed Native American mothers about their life circumstances and culture. I was most interested in the interaction between ruralness, culture, poverty, and the provision of early childhood special education services. However, I mostly wanted participants to relate their own story-to reveal their experiences with the advent of children with special needs.

Method

Participants

In this initial phase of an ongoing project, two mothers consented to be interviewed. Each is described below.

Eloise was 36 years old. She lived in a large, comfortable farm house, with her husband Josh. Their home was in a rural area, situated in a beautiful pine and birch forest, though within 10 miles of a sizable town. Both were enrolled members of Ojibweyan groups, but from two different upper Midwestern reservations. Eloise and Josh were both extremely active in Native American culture; they and their children related lively participation in tribal and inter-tribal ceremonies and gatherings.

I found Eloise to be articulate and passionate about her son's special needs. For the most part, she spoke quickly and animatedly, though her speech slowed and became softer, seemingly more contemplative in tone, as she spoke of spiritual aspects of Dave's condition.

Dave was 6 years old at the time of the interview. He had received early childhood special education and infant services from birth. Oxygen deprivation suffered at birth left Dave with seizures, developmental delays, and low muscle tone. The latter condition produced problems with eating and swallowing, putting him at risk for choking. It was not clear whether or not Dave will evidence learning disabilities in the future. Although his cognitive and behavioral milestones were below average, his prognosis was positive, a situation quite different from what Eloise and Josh were told shortly after Dave's birth.

The second participant was 44 years old, considerably older than Eloise. Sara lived in a sizable Midwestern town (population approximately 12,000). We met at the local high school so I have yet to observe her on her home turf.

Sara spoke more deliberately and directly than did Eloise. Perhaps at least in part because she reported being in a hurry, Sara made her points succinctly and provided few overt cues regarding her emotional status. Nonetheless, she appeared relaxed and engaged as we conversed.

Albert was Sara's foster child, for whom she has been responsible off and on nearly from his birth. He was five years old at the time of the interview, and evidenced severe visual impairment and behavioral problems. In addition, some mild-to-moderate cognitive deficits were evident. Albert may have been born addicted to crack cocaine (Sara voiced this); he was an irritable, difficult infant, according to Sara. She heard about early intervention services through another Native American mother.

Procedure

Approval for the study was obtained from the director of a rural special education cooperative in a northern state which served several school districts. Some of those school districts serve Native American children whose families live on or near three different reservations. Letters inviting participation were sent through the Early Childhood Special Education program to Native American

mothers. Mothers who responded to the letters were contacted to arrange interviews.

Mothers read and signed consent forms agreeing to be interviewed and tape recorded. Participating mothers were allowed to see and edit a transcript of their interviews. In both cases, participants accepted the transcripts as presented. The language of the informed consent form stressed confidentiality, which was also emphasized during initial contacts with prospective participants.

Interviews were held in the participant's home (Eloise) or a neutral place where they reportedly felt comfortable (Sara). A brief list of general questions was used as a guide only to help ensure uniformity of material covered with each participant. Every effort was made not to lead participants to any preconceived ideas; conversations were allowed to flow as normally as possible.

Analysis

Tape recordings of the conversations were transcribed by hand. Three codes appeared to capture thematic similarities across interviews. These themes served as a heuristic for organizing results, and were treated as themes in the analysis.

Results

Analysis of the coded interviews revealed several common themes. Those experiences viewed as "successes" by mothers are described in an initial section. "Obstacles," the second subheading, were also encountered by mothers. The role of culture was experienced differently by each participant. One (Eloise) was more willing to describe her views regarding cultural issues. Culture is the third theme. Though I expected ruralness to be an issue, mothers' comments revealed other concerns and problems related to this theme than had been expected, though the theme of distance from a large metropolitan area (approximately 270 miles) was intertwined with the larger obstacles theme.

Successes

Each mother voiced clear successes resulting from ECSE services, though the specifics differed. In each case, the early childhood special education professional was viewed as genuine, knowledgeable, and capable of sharing that knowledge without pretense or criticism of the families. "She was great," related Sara. In a similar vein, Eloise offered the following statement:

She was very non-judgmental. It was frightening for me to have someone come into my home at a time when I was spending all of my time basically feeding Dave and doing therapy with Dave. Our house was kind of crazy during that time. She made me feel so comfortable, and this is really saying something because it's a touchy thing for me. I

felt comfortable enough for her to come into my home at any time no matter what it looked like, no matter what I looked like. She didn't judge us. She just supported us and almost nurtured me, in a way, at a time when I was so frightened. I was so afraid he'd die at any time. To have somebody work with us who was so gentle, so reassuring and non-judgmental, was great. I really feel that we were just blessed to have had her. For a non-Native American person to come into our home and for us to feel so comfortable with her is, I think, really high praise."

These mothers' comments serve as eloquent testimony to the success of the professionals who provided services for them. It appears that personal style is important to the success of ECSE programs.

Dave and Albert's conditions both improved as a result of timely and consistent early intervention services. Albert came to Sara as a foster child at age 2 months. "He was diagnosed as being blind at birth. Through the grapevine we heard that he was a crack baby. When he came he was real irritable and I was real worried about him. (The early intervention therapist) gave me some ideas on how to cuddle him and she was real helpful. About the time he was 3 years old," here Sara pauses, "He started tracking! That just really gave me the feeling that I was going to do something good for this baby. Through the early intervention program [I could] just see the progress that he was making."

Dave's mother expressed similar feelings about improvements resulting from the intervention program. "We did see some improvement. His seizures and apnea stopped at about one year old. He started to learn to walk and talk. I would say that I credit early intervention with really being the magic key for Dave. We had this window of opportunity at a really young age. He would be a totally different child today if it wasn't specifically for (the early intervention occupational therapist) and what she did with us, and did it right away so young. That window of opportunity would have been lost by the time he entered school."

Obstacles

Mothers expressed a wide variety of obstacles to the effectiveness of early intervention services. Under this code I noted (1) problems with distances from appropriate medical services, (2) perceived failure of physicians to listen actively and sensitively, (3) and trust issues engendered by cultural differences.

Distance. Both Sara and Eloise mentioned that appropriate medical care, especially needed specialists, was not available locally, engendering substantial investments of time and energy in travel. Sara noted that, "The doctor said he'd never be able to [write his name] and now he is reading, he is writing his name and watching TV."

According to Eloise, the medical professionals were also pessimistic concerning Dave. "They said he wouldn't walk and wouldn't talk, and (until 2 1/2) that is exactly what we were seeing." Medical opinions expressed to these mothers offered little hope and, perhaps most significantly, few targets or goals toward which care could be directed.

Active Listening. Valuable information was missed, according to Eloise, when doctors failed to truly listen to her needs. She related the following story in an excited, emphatic tone:

... I'd take him into the doctors and say we really have a problem here. I think something is wrong. It doesn't feel right to me. I've had 4 other children of my own. I've cared for many other foster children. Something is not right here. And the doctors wouldn't listen to me.

With support from the early interventionist, Eloise continued to seek a doctor who would listen until she found one. She had to travel to a large city to find medical professionals who would listen. "We found out afterwards that at times when I believed he had pneumonia ... and the doctors wouldn't listen to me ... he was aspirating into his lungs and getting pneumonia. With (early intervention) support, I started insisting on chest X-rays when I felt he was having pneumonia and found out I'd been right. He could've died."

Trust and Culture. A major obstacle described by both mothers was trust. Eloise said, "There's a lot of trust issues. I think that [when we had early intervention services] we were the only Native American family that had allowed early intervention people to come into the home to work with our child." Sara described her first early intervention team meeting. "I was kind of intimidated when they first came out. I didn't know what to expect. A few of them were really dressed to the max. They were so formal with me and the big words and all. It took awhile for it to sink in."

Eloise addressed the history between Native- and Euro-Americans. "There are many people in their family history who know that if there were children born on the reservation, people would come in and say the parents were poor and they were Indian and they would take the children away. They never saw (their children) again. I know many families that have had histories like that. Also, if you had a child with a disability they came and took the child. The parents didn't have to be neglectful, abusive, or alcoholic for this to happen."

On the reservation, parents can select between schools emphasizing traditional Native American culture and public programs. For both mothers, this proved a difficult decision. Eloise and Sara expressed that the tribal schools offered better cultural grounding, but they also stated that the public schools offered better educational services. Selecting one alternative over the other was frustrating.

Eloise argued that Native American traditional values contributed positively to Dave's care. "It's a cultural thing for us to have our babies sleep where we are. We had a swing for Dave right above our bed, but at first I wouldn't even let him be in that. If he had been in another room in a crib when we brought him home and he stopped breathing, I would have never known. He would have been a SIDS [victim]."

Spiritual feelings and experiences are difficult for many people to talk about, regardless of background. Dave's birth altered Eloise's feelings about the Creator. "I had always had a trust that the Creator was always with us and would help us no matter what happened. When Dave was born I thought we were going to die. I don't know what happened to me, but I just didn't have trust any more in anything." Some time later she went to a "spiritual gathering for women" where she cried as she remembered the frightening experience of Dave's birth and early problems. A friend at this gathering helped her to see that, "It wasn't the Creator that let it happen or made it happen. She said the Creator stepped in ... and saved him [Dave] because he is meant for something really important."

Another cultural tradition that provided strength for Eloise came from the family's medicine man. "When we can't find something out with western medicine, we go to our medicine man. I feel lucky that we have him to go to. When you are working with a Native American family, you should have respect for those beliefs. It's not a voodoo doctor, a witch doctor, or superstitious mumbo-jumbo. To us it's very real." The medicine man visited Dave in the hospital, where he gave doctors his judgment on the status of internal organs and the effect of their functioning on his survival. Without lab reports having been done, the medicine man's diagnosis matched that of medical doctors, to outsiders' amazement.

Summary and Conclusion

The successes enumerated by the mothers were related to specific roles of the ECSE practitioner (the same individual in both cases). First, she was skilled at her craft, comfortable with her therapeutic role. Second, she advocated for mothers and caregivers when tribal members found it necessary to interact with bureaucracies and medical professionals. Finally, caregivers who listen carefully and evidence respect for traditional cultural values enjoyed the trust of Native American mothers.

Perhaps the most important aspect of the training of early childhood specialists representing all the disciplines are development of advocacy and active listening skills. In addition, it is important that such individuals be taught the culture and lore of all the local subcultures, including Native Americans.

It may be important for ECSE practitioners to take the lead in integrating or coordinating tribal and public programs. As I look back on the interview, this choice was one of the most difficult faced by both mothers, but especially for Eloise who, at

times, felt she was pulled between loyalty to the tribal school and what she felt was best for Dave. This type of gut-wrenching decision should not be added to the burden of mothers or caregivers of at-risk infants.

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